



Patient Determined Disease Steps (PDDS)

The Patient Determined Disease Steps (PDDS) is a self-assessment scale of multiple sclerosis disease status collected in the North American Research Consortium on Multiple Sclerosis (NARCOMS) Registry at enrollment and semi-annual follow up surveys. The PDDS is not a copyrighted instrument, however the authors of PDDS request that if you use the PDDS as given below or from www.NARCOMS.org/PDDS that NARCOMS be acknowledged when using or publishing work with these questions and that the following references be cited:

PDDS:

Hohol MJ, Orav EJ, Weiner HL. Disease Steps in multiple sclerosis: A simple approach to evaluate disease progression. *Neurology* 1995; 45: 251–55.

Hohol MJ, Orav EJ, Weiner HL. Disease Steps in multiple sclerosis: a longitudinal study comparing disease steps and EDSS to evaluate disease progression. *Multiple Sclerosis* 1999; 5: 349–54.

Marrie RA and Goldman M. Validity of performance scales for disability assessment in multiple sclerosis. *Multiple Sclerosis* 2007; 13: 1176-1182.

Acknowledgement for use:

The PDDS is provided for use by the NARCOMS Registry: www.narcoms.org/pdds. NARCOMS is supported in part by the Consortium of Multiple Sclerosis Centers (CMSC) and the CMSC Foundation.

We hope the PDDS is useful in your studies, and appreciate the above citations and references.

A handwritten signature in black ink that reads "Robert Fox".

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PDDS: Patient-determined Disease Steps

Please read the choices listed below and choose the one that best describes your own situation. **This scale focuses mainly on how well you walk.** You might not find a description that reflects your condition exactly, but please mark the **one** category that describes your situation the closest.

0 **Normal:** I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.

1 **Mild Disability:** I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.

2 **Moderate Disability:** I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.

3 **Gait Disability:** MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack.

4 **Early Cane:** I use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks.

5 **Late Cane:** To be able to walk 25 feet, I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.

6 **Bilateral Support:** To be able to walk as far as 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.

7 **Wheelchair / Scooter:** My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet, even with crutches or a walker.

8 **Bedridden:** Unable to sit in a wheelchair for more than one hour.